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Nothing about us without us: the importance of local collaboration and engagement in the global study of autism

Rosa A. Hoekstra,¹ Fikirte Girma,² Bethlehem Tekola³ and Zemi Yenus⁴

¹Lecturer in Psychology, Department of Psychology, Institute of Psychiatry, Psychology and Neuroscience, King's College London, UK; email rosa.hoekstra@kcl.ac.uk

²Psychiatrist and assistant professor, Department of Psychiatry, Addis Ababa University, Ethiopia

³Postdoctoral researcher, Department of Psychology, Institute of Psychiatry, Psychology and Neuroscience, King's College London, UK

⁴Founder and director of Joy Autism Center, Addis Ababa, Ethiopia

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Our current understanding of autism and other developmental disorders is primarily based on research conducted in high-income countries, predominantly in North America and Europe. Even within high-income countries, White participants are overrepresented in autism research. There is now increased recognition that a more global and diverse research representation is warranted. This paper argues that in order for global and diverse research efforts to be effective, it is essential to collaborate and engage with local experts and stakeholders, including local researchers, clinicians and representatives from governmental and non-governmental organisations. Such collaborations ensure that studies use culturally appropriate methods and materials, and that research findings are interpreted taking local context into account. Ultimately, these collaborations build local capacity and foster the development of culturally and contextually appropriate interventions that address locally perceived needs. The adage 'nothing about us without us' is vital to global autism research.

Mental health problems and developmental disorders affect 10 to 20% of children globally (Kieling *et al*, 2011). Although 90% of all children live in low- and middle-income countries (LMIC), most child mental health research is conducted in high-income countries (HIC) (Kieling *et al*, 2011), and fewer than 7% of developmental psychology studies are from non-Western countries (Nielsen *et al*, 2017). Although the gap in global mental health research was highlighted more than 15 years ago (Patel & Sumathipala, 2001), its relevance and importance to the study of child development and autism has only recently started to receive attention (Durkin *et al*, 2015; Nielsen *et al*, 2017). Most autism research is conducted in North America and Europe, with only a small proportion of studies coming from LMIC. This research divide has two important drawbacks (Durkin *et al*, 2015). First, our knowledge of autism and its causes may be incomplete and biased. Second, because research is often linked to capacity building, the lack of research in

LMIC is likely to contribute to a growing inequity in access to evidence-based services and support.

There is currently a real impetus for global research on autism and other developmental disorders. The journal *Autism* recently published a special issue on Global Autism Research, and several funding mechanisms, including the Global Alliance for Chronic Diseases and the UK's Global Challenges Research Fund, explicitly welcome applications related to mental health and developmental disorders in LMIC. To effectively capitalise on the increased attention paid to global autism research, this paper argues for HIC researchers to collaborate with local partners. Over the past 5 years, our team – based in Ethiopia and the UK – has conducted a set of studies on autism and other developmental disorders in Ethiopia. The key lesson we learned was the importance of engagement with local researchers and a wider group of stakeholders, including clinicians and representatives from governmental and non-governmental organisations (NGOs). We present examples from our experiences to illustrate how, without this local collaboration, our efforts could have been counterproductive, potentially resulting in research findings that were biased or in interventions that were ineffective or even harmful.

The case for using local expertise

First, working with a team of local researchers and stakeholders ensures the use of culturally appropriate research methods. Data collection methods common in HIC, such as paper-and-pen questionnaires or online surveys, are less suitable for use in LMIC such as Ethiopia, owing to low literacy rates and a strong oral tradition. Previous research led by Ethiopian colleagues (e.g. Shibre *et al*, 2006) indicated that completion of a questionnaire through a face-to-face interview with a lay interviewer is a culturally appropriate alternative. The local researchers in our team guided the design of these study aspects, including appropriate training for the lay interviewers (Tilahun *et al*, 2017a, b).

Similarly, local expert input is needed to ensure that questionnaires fit local cultural norms and context. For example, we found that the anchoring of items of a caregiver involvement measure, originally developed in the USA,

required cultural adaptation. Whereas enthusiasm tends to be displayed openly in the USA, equivalent levels of involvement will typically be shown in less overt terms in Ethiopia. Thus, the anchors providing examples of what typifies a 'very enthusiastic' or a 'not enthusiastic' caregiver required adjustment.

Local perspectives may also prove essential when interpreting research findings. Our survey in caregivers of children with developmental disorders indicated that the practice of restraining a child is relatively common (Tilahun *et al.*, 2016). Subsequent discussion of this finding during a stakeholder workshop taught us that restraint is not typically used as punishment, but a last-resort measure to protect the child from harm when there is no one to look after the child (Tekola *et al.*, 2016). Thus, these results should not be interpreted in terms of abuse, but rather in the light of lack of available support. Consequently, efforts to reduce restraining of children with developmental disorders are more likely to be successful if they focus on improving support and care systems for families, rather than an education intervention solely conveying the message that restraining is harmful.

Local input is also essential when designing interventions. When we developed the mental health module of an education programme for Ethiopian community health workers (Tilahun *et al.*, 2017b), local experts indicated that we should not emphasise the strong genetic influences on conditions such as schizophrenia and autism. An emphasis on high heritability could have had the unintended consequence of replacing existing stigmatising beliefs in the community with stigma associated with a 'genetic taint'.

Perhaps most importantly, local collaboration and engagement are essential to ensure that the intervention addresses a locally perceived need, suits the country's health and education system, and is supported by local stakeholders. For an intervention to be sustainable and have scope for scale-up, the programme needs to be 'owned' by local partners. In an ongoing project, we are adapting and evaluating a parent skills training (PST) programme, developed by the World Health Organization, for use in Ethiopia. We set up a PST adaptation advisory board, consisting of local experts and stakeholders, who over the past 2 years have provided invaluable feedback on the draft content and delivery of the programme. Without local input, the training could have inadvertently set wrong expectations (e.g. that the intervention may result in a cure; Tilahun *et al.*, 2016), glossed over pertinent local issues or used culturally inappropriate intervention strategies.

Finally, working with local universities contributes to capacity building for research in the country. Although global research has burgeoned, recent analyses (Kelaher *et al.*, 2016; Nielsen *et al.*, 2017) suggest that the scientific

articles reporting on these studies are primarily written by researchers from HIC. HIC researchers should invest in collaborating with local researchers and the training of local students, making sure they get the opportunity to write papers and submit to international peer-reviewed journals. These researchers and students are likely to take up prestigious posts and be involved in training future cohorts of local experts, thereby allowing for future expansion in research and mental health services.

How to achieve local collaboration and engagement

In many LMIC, in the absence of comprehensive governmental services, grassroots NGOs have been founded to address pertinent needs. The last author of this paper (Z.Y.) established Ethiopia's first autism school; following her pioneering work, additional schools for children with developmental disorders have opened (Tekola *et al.*, 2016). A useful way to initiate a local network is through these local organisations, because they will have wide-ranging practical experience and knowledge of the challenges faced by local families. Connections with researchers can be built through local universities. Local researchers do not (yet) have to be autism experts; a public health or mental health researcher will still be well qualified to give input in locally appropriate research methods and study designs. It is this mix of partners that is important: local stakeholders are experts in the perceived needs and practical considerations, but are less well placed to comment on research techniques; in turn, researchers may miss subtle issues with research instruments if they are not also scrutinised by stakeholders with first-hand experience with autism.

The optimal method for local engagement will depend on the culture and context. Low literacy rates and poor internet access make written consultations less suitable for use in Ethiopia. In our experience, face-to-face workshop-style stakeholder consultations work best (Tekola *et al.*, 2016). Once a network is established, it is important to sustain it by keeping stakeholders involved in each step of the research process, from the study design phase, through regular progress updates, to presentation of preliminary findings and dissemination of the final research report.

Global benefits of local collaboration and engagement

Although the preceding paragraphs illustrate our experiences in one particular low-income country, these are likely to have relevance more widely. High levels of stigma (Divan *et al.*, 2012) and lack of culturally appropriate screening and diagnostic tools (Durkin *et al.*, 2015) and interventions are prominent issues in most LMIC. Research in LMIC might also inform strategies to improve access to services and research in hard-to-reach groups within HIC. Ethnic minorities are under-represented in research in HIC (West *et al.*, 2016);

autism tends to be underdiagnosed and diagnosed late in children of ethnic minorities, and parents of these children report receiving lower-quality healthcare (Magaña *et al*, 2015). Research findings from LMIC might thus provide clues to how to better reach these under-served groups in HIC.

In fact, the call for inclusion of local partners in research equally applies to research in hard-to-reach groups within HIC. Researchers and students from ethnic minorities are underrepresented at research-intensive universities. The inclusion of such groups in research teams is more likely to lead to innovative research designs that will promote successful recruitment and retention of diverse participants in research studies.

Conclusion

For research in under-served communities to be successful (whether in LMIC or in subgroups in HIC), researchers at elite universities in HIC need to make serious efforts to engage with academics and stakeholders that reflect the community they wish to study. Only through this ‘nothing about us without us’ approach can we ensure that our research uses culturally appropriate methods and materials, and that findings are interpreted according to local cultural context and result in sustainable interventions that address locally perceived needs.

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